

## Family or Informal Caregiver Support

### Early Stages of Dementia

#### Goal

- The caregivers are identified and given information, education and support in accordance with their wishes/needs

#### Key Assessment Issues

##### General

- Family may be unaware of problems because person covers up from fear, denial or not seeing need to involve family in health changes
- Family members may be the ones to express initial concerns due to observed changes in the person, primary caregiver or both
- Changes occur in family dynamics

##### Self Care/Well Being

- Caregiver may be experiencing stress that could be leading to health risks stemming from a variety of factors: e.g., uncertainty of situation, increased dependence of care recipient, increased isolation of caregiver, tendency to focus on care recipient's health and needs not own, and guilt over or lack of knowledge about seeking help

##### Education/Skill Building

- Caregiver and family members may mistakenly think person's symptoms are part of normal aging

#### Possible Interventions

##### General

- Encourage person to inform family of the problems they are experiencing or allow you to do so
- Assist in obtaining a complete expert cognitive and physical evaluation for person with dementia, with thorough explanation of results provided to caregiver and family
- Determine caregiver/family's immediate desires for information and address these first – it is critical to “dose” information so it is the given in the right amount at the right time in order for it to be utilized

##### Self Care/Well Being

- Suggest caregiver receive a health evaluation for stress risks if indicated – especially if she has chronic or limiting conditions
- Emphasize importance of caregiver self-care, and willingness to accept support – educate about risks of catastrophic illness when caregivers don't take care of own health and needs, and risks to care recipient as well
- Identify individuals in the person's and caregiver's lives who can provide informal support, connections to continued meaningful activities, opportunities for shared fun/happiness together, and respite
- Assist caregiver in developing a plan for using resources, help, respite, maintaining own physical and mental health
- Encourage caregiver to identify a confidant or friend for ongoing personal support
- Suggest mental health evaluation or counseling for the caregiver, if indicated (successful caregivers recognize the need to begin self-care early and continue practice)
- Encourage caregiver to discuss intimacy issues, the effect the illness has on care recipient's sexuality and on their relationship

##### Education/Skill Building

- Educate caregiver on the illness, stages, importance of thorough evaluation, medication trials and future expectations
- Refer family and caregivers to local Alzheimer's Association chapter for counsel, support groups, information, etc.

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# Family or Informal Caregiver Support

## Early Stages of Dementia (continued)

### Goal

- The caregivers are identified and given information, education and support in accordance with their wishes/needs

Key Assessment Issues	Possible Interventions
<p><u>Education/Skill Building</u></p> <ul style="list-style-type: none"> <li>• Family may know about the dementia diagnosis but not understand about the consequences resulting from the progression of the illness</li> </ul> <p><u>Relationship with Care Recipient</u></p> <ul style="list-style-type: none"> <li>• Caregivers may be confused about their role change from spouse or child, to caregiver</li> <li>• Grief and/or fear may prevent family from visiting/interacting with person</li> <li>• Person with dementia may deny problems, withdraw, etc., and cause rifts in relationships; or insist caregiver or family not seek diagnosis or help</li> </ul> <p><u>Family System</u></p> <ul style="list-style-type: none"> <li>• Family members will express wide range of reactions, emotions, and opinions on the extent of the problem(s)</li> <li>• Some family members may minimize, deny or cover up problems and/or risky or dangerous situations associated with the disease, e.g., driving ability</li> <li>• Long distance caregivers/family members may recognize changes more readily than family/caregivers who see the person frequently. This can create “holiday syndrome” of sounding alarm for care intervention when they visit, and resulting family conflicts</li> </ul>	<p><u>Education/Skill Building</u></p> <ul style="list-style-type: none"> <li>• Discuss options for future planning – need for support, safety, alternative living choices and professional help with medical, education legal, financial planning, etc. (see care planning area # 6)</li> </ul> <p><u>Relationship with Care Recipient</u></p> <ul style="list-style-type: none"> <li>• Discuss emotional shifts/changes that occur for caregiver when current role &amp; relationship with care recipient (spouse/child) changes to total care or “parental” role</li> <li>• Explain how options for targeted help (personal care, bathing, etc.) can reduce stress and help preserve relationship</li> <li>• Encourage initial planning for future with the person who has dementia - to reflect wishes of person and family. Include plans for activities person may want to do before impairment prohibits the activity (e.g., special trip, etc.)</li> <li>• Encourage caregiver to allow person with dementia to remain as independent as possible, to continue tasks that maintain function and self-esteem, to monitor for frustration and to provide cueing/assistance that allows the person with dementia to be successful</li> <li>• Encourage significant people in care recipient’s life to record person’s history, habits, preferences, stories, fond and traumatic experiences, etc., for future reference</li> </ul> <p><u>Family System</u></p> <ul style="list-style-type: none"> <li>• Encourage family meeting to inform all family members of future planning and identify who is available to assist with which care needs. Encourage person to discuss needs and wishes during the family meeting</li> <li>• Discuss care recipient and caregivers past and present relationships, screening for domestic violence/abuse and other forms of trauma which may need to be addressed</li> <li>• Assist the family through education about the disease, cognitive changes to expect, changing roles and responsibilities, and how to best support the person</li> <li>• Include long distance family/caregivers in regular updates on person's status.</li> </ul>

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## Family or Informal Caregiver Support

### Middle Stages of Dementia

#### Goal

- The caregivers are supported to enable them to maximize caregiving role while maintaining health and appropriate balance in personal life

#### Key Assessment Issues

##### General

- Caregiving duties and their toll on caregiver become more intense in middle stages, risks to caregiver are higher

##### Self Care/Well Being

- Caregivers may experience compromised emotional, psychological and physical well-being; ability to cope and plan for self-care – role confusion may deepen as personal care tasks are taken on
- Caregiver may feel social isolation
- Caregiver may be providing 24-hour per day supervision without relief or respite

##### Education/Skill Building

- Caregiver may experience difficulty planning/ identifying activities for the person
- Caregivers may experience difficulties in managing the person's behavior symptoms
- Caregiver may have concerns regarding finances and the future

#### Possible Interventions

##### General

- Develop an overall strategy to be supportive of the caregiver while educating about risks and options for assistance
- Determine caregiver/family's immediate need for information and "dose" it - the right amount at the right time

##### Self Care/Well Being

- Encourage caregiver to understand that they have choices as to the level of care they want to provide, and identify their caregiving parameters. Assist in obtaining targeted help for areas of care the caregiver is uncomfortable with or most stressed by
- Assist caregiver in identifying ways to build ongoing self-care and support: friends, support group, counseling, rest and respite, good medical care, regular exercise
- Inform caregiver of services, opportunities and resources available to help cope with ongoing losses, intimacy and sexuality issues, etc.
- Encourage continuation of the caregiver's interests, hobbies, etc.
- Encourage caregiver to increase involvement with family, friends and natural supports in providing care/connections for the person
- Encourage and arrange respite options
- Be sensitive to and support caregiver's capacity to continue caregiving

##### Education/Skill Building

- Establish support system for caregiver and family to access immediate assistance for problem solving, e.g., Alzheimer's Association help-line, church, other family members/friends
- Assist caregiver/family in accessing community resources
- Model supportive dementia caregiving techniques with the person - to assist caregiver in understanding and using appropriate dementia caregiving skills
- Educate caregiver on concept of "least restrictive interventions" (e.g., medications, restraints, etc.) for person, and how to advocate for the person's care
- Encourage planning for alternate placement, and ongoing legal and financial planning (See care planning area # 6)

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# Family or Informal Caregiver Support

## Middle Stages of Dementia (continued)

### Goal

- The caregivers are supported to enable them to maximize caregiving role while maintaining health and appropriate balance in personal life

### Key Assessment Issues

#### Relationship with Care Recipient

- Caregivers experience loss and grief, e.g., in having lost the shared meaning, recognition, role identity and support in decision-making from the relationship they had with the care recipient
- Caregiver must constantly do the thinking and planning for the person with dementia

#### Family System

- Family members may stay away, not know what kind of help to offer, be critical of caregiver's efforts or grieve loss of relationship they knew with person who has dementia

### Possible Interventions

#### Relationship with Care Recipient

- Help caregiver recognize person's diminished ability to learn new things/retain new information can be compensated for
- Provide information about reminiscence, meaningful activities, life-story book, task breakdown, prompts, security of routines and how to avoid creating excess disability
- Help caregiver realize the recipient reverts backwards in time orientation, thinking he is a younger age in an earlier time in his life - and to honor the past as his present, the importance of being able to shift with the person to reassure and enjoy time together.
- Educate the caregiver on the value of recording the care recipient's early life history – significant people, experiences, events, habits, interests, etc. - for use by caregivers that do not know recipient and/or history. Be sure to include significant traumas or difficult events from the person's past that may come up – as repetitive themes - when person experiences stress or triggers to these memories

#### Family System

- Assist caregiver and family in realizing ways that family can become involved with household and caregiving duties, and in meaningful activities with the care recipient
- Acknowledge perspectives of family members who visit infrequently and see person's decline more sharply; offer support with reactions

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## Family or Informal Caregiver Support

### Late Stages of Dementia

#### Goal

- The caregivers are supported to continue meaningful caregiving role while coping in healthy ways with end of life issues

#### Key Assessment Issues

##### General

- Caregiver and family members may have difficulty coming to terms with person's need for placement in a skilled care facility

##### Self Care/Well Being

- Caregiver may have difficulty proceeding with life after placement of person
- End of primary caregiving role may cause caregiver to have difficulty with role expectations, to feel demoralized, and/or extremely guilty

##### Relationship with Care Recipient

- Caregiver may experience difficulty visiting/interacting during late stages of the disease

##### Family System

- Families are often faced with making difficult medical and life ending decisions, such as use/non use of antibiotics, tube feeding, etc.
- Families may participate fully in hospice care
- Families and/or Dr. may have forgotten - or may not have recently reviewed - person's end of life preferences

#### Possible Interventions

##### General

- Educate, advise, and support family regarding the timing of and need for placement
- Encourage collaborative care relationships and activities between service providers and family

##### Self Care/Well Being

- Offer support, encouragement and ideas to caregiver regarding ways to "fill time" after person's placement
- Encourage caregiver and family to remain involved in support systems and friendships to maintain continuity and caring resources for themselves after person's death
- Encourage family to continue to seek support and engage in discussions so that they can stay involved and continue to have person's end-of-life wishes honored
- Inform family of bereavement services available to them to cope with grief, before and after death of person

##### Relationship with Care Recipient

- Inform caregiver/family that person's senses remain intact late into the disease. Help them to facilitate meaningful sensory interaction with person, e.g., aroma therapy, by applying lotion, giving back or hand massage, listening to familiar music, etc. - which can be beneficial to the person and the relationships (see planning area # 4)
- Assist families in their experience of transition to end stage process, physical and emotional care issues, and access to hospice care when appropriate

##### Family System

- Advocate for interventions between facility and family as well as other services to address feelings and role changes of family
- Advocate for conversations with physician and formal caregivers regarding end-of-life issues/person's wishes and advance directives (see care planning area #6)

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